



Making decisions

Helping people who have difficulty deciding for themselves

A guide for healthcare professionals



M

9004

Lord Chancellor's Department May 2003

**WELLCOME
LIBRARY**

General Collections

M

9004



22503124712

Contents

	Page
About this booklet	2
1. Defining and assessing mental capacity	3
2. Best interests	8
3. Healthcare decisions	9
4. Applications to the High Court	13
5. Combating abuse, exploitation and neglect	15
6. Further guidance and information	
Hints for determining best interests	17
Extract from the judgement in the case of <i>Ms B</i>	19
Further guidance	22
Useful organisations	25

About this booklet

This booklet has been prepared by the Lord Chancellor's Department to help doctors, nurses, and other healthcare professionals involved in the care and treatment of adults who need support to make decisions. That support may be required because of learning difficulty, brain injury, dementia, mental health problems or any other illness or disability which affects the person's mental capacity.

The booklet explains the current legal position and lists sources of further professional guidance and relevant organisations.

The booklet does *not* cover:

- ▶ the care and treatment of children and young people (aged up to 18), although some of the issues discussed here may be relevant; or
- ▶ the assessment, admission to hospital and compulsory treatment of patients for mental disorder or guardianship of clients under the Mental Health Act 1983. Separate guidance on this is given in the *Mental Health Act: Code of Practice* (Department of Health, 1999).

The information contained in this booklet relates only to England and Wales.

1. Defining and assessing mental capacity

The right to make decisions

Every adult has the right to make his or her own decisions about health, legal, financial and other matters and is assumed to have capacity to do so unless it is proved otherwise. Very few people – even those with severe disabilities and high support needs – are totally unable to make such decisions. For example, a person with severe learning disabilities or who is unable to use speech, may indicate by their behaviour whether they are happy to be admitted to hospital or residential care.

Even with help and support, however, some people do lack capacity to make some decisions and these may need to be taken for them. An assessment must be made in each case, for each particular decision. For more serious or complicated decisions, a more formal assessment of capacity may be needed.

Defining capacity

The law generally looks at the capacity needed by the person to make a particular decision. For some people (for example, those with dementia) the loss of their ability to cope may be a gradual process, so the point at which they are no longer able to make a decision is difficult to pinpoint. The capacity of others, such as individuals with mental health problems, may fluctuate over time.

Whether someone has or lacks capacity to do something may ultimately be a question for the courts to answer. Opinions of the family, social workers, solicitors and doctors all help the court to reach a conclusion. In practice, however, health professionals make these judgements all the time and act on their assessments in the vast majority of cases.

There are different tests for assessing capacity depending on the decision or action that needs to be made or taken.

When assessing a person's capacity to make a decision, doctors must be aware of the nature of the particular decision the patient is being asked to make, and whether there is a specific legal test of capacity to make that decision.

Capacity to consent to medical treatment

Patients have a right to determine what happens to their own bodies and consent must be obtained, if the person is able to give it, before starting treatment. The courts have held that an adult has capacity to consent or refuse consent to treatment if:

- ▶ he or she can understand and retain the information that is material to the decision, especially the likely consequences of having or not having the treatment in question; and
- ▶ he or she can use the information and weigh it in the balance as part of the process of arriving at the decision.

The courts have said that a refusal of treatment will not be valid if *'the patient's will has been overborne by another's influence'*.

Who can assess capacity?

The person (this could be a healthcare or other professional, relative or carer) who needs consent will be the first to consider whether the person concerned has the necessary capacity to give it. For example, in legal matters or transactions, such as making a will or an Enduring Power of Attorney, the solicitor concerned will need to be satisfied that the person has capacity before any documents are signed. If he or she thinks it is necessary, the solicitor will seek an opinion on the person's capacity from a doctor or psychiatrist.

Where consent is needed for medical examination or treatment, the doctor or other healthcare professional suggesting the treatment will need to decide whether the patient has the capacity to consent or to refuse consent. For some medical disorders or disabilities it may be necessary to consult the person's GP or to request an assessment from a specialist practitioner, such as a psychiatrist or a geriatrician, with the relevant expertise.

When would a doctor's assessment be necessary?

A doctor's assessment may be necessary:

- ▶ to make an assessment of capacity to consent prior to medical examination or treatment
- ▶ to provide a medical certificate, for example at a solicitor's request, concerning a person's capacity to make a decision unrelated to medical treatment

- ▶ to witness a signature or otherwise certify a legal document; or
- ▶ to give an opinion about a person's legal capacity which is relevant to court proceedings.

How is capacity assessed?

Doctors must consider whether the person has the necessary capacity to make each particular decision at the time that it has to be made. They must consider how much information to convey to the person and how to make the most of the abilities that the person has.

Before giving an opinion, the healthcare professional should make every effort to help and support the person to maximise their potential to make their own decisions or at least to participate as fully as possible. For example, they should choose the best time and location for the assessment or allow the person sufficient time to become familiar with the issues concerning, or information relevant to, the decision. They should communicate the information in simple language or through the use of pictures and photos, for example where the person has a learning disability.

Depression or low self-esteem can be common where people have other disabilities: this is not always recognised but it could affect a person's capacity. A person with dementia may lack capacity at the time of one assessment but the result may be different if a second assessment is made during a lucid interval.

Medical treatment

Doctors proposing treatment for a patient have a personal responsibility to judge whether that person has capacity to give consent and a duty to explain to him or her the treatment, the benefits and risks and any alternatives.

The doctor who performs the treatment or examination has ultimate responsibility for ensuring that an explanation has been provided to the patient and that their consent has been obtained, involving other members of the clinical team where necessary. Where there is doubt – or where an opinion is requested – about a patient's capacity to make a particular decision, any assessment of capacity should be carried out by a doctor.

Expert sources of help, such as speech or occupational therapists and independent advocates, may be able to help with communication or suggest alternative methods to convey information. They may also help the person to express their wishes and aspirations and to make choices. Some organisations have produced publications, tapes and other materials which may help. Contact details for these and advocacy organisations are at pages 25–31.

Further guidance

See pages 22–23 under:

▶ ***Assessing capacity***

Best interests

Consent to examination and treatment

2. Best interests

Healthcare professionals can and should provide treatment without consent for people who lack capacity to consent, if it is considered to be clinically necessary and in the ‘*best interests*’ of the patient. The benefits should be weighed against the burden of undergoing that treatment, but it should not be given if the patient has made a valid advance refusal (see pages 10–12). Healthcare professionals have no authority to make any other sorts of decision, such as personal or welfare decisions.

In relation to medical treatment, the High Court has ruled that best interests are not confined to best medical interests, but must take into account ‘*the patient’s values and preferences when competent, their well-being and quality of life, relationships with family or other carers, spiritual and religious welfare and their own financial interests*’.

In general, determining someone’s best interests means trying to find out what is best for them, what is most important to them, and what they would have wanted, *not* what would make life easier for people involved in their care. A list of hints to help in determining best interests is at pages 17–18. Best interests are assessed by the healthcare professional who is going to give the treatment.

Further guidance

See pages 22–23 under:

- ▶ **Assessing capacity**
- ▶ **Best interests**

3. Healthcare decisions

Who can consent to medical treatment?

No one – husbands or wives, partners, close relatives, professional carers or independent advocates – can legally give or withhold consent to medical treatment on behalf of another adult and should never be asked to sign a consent form on behalf of another person. However, relatives and carers *should* be consulted about the patient's best interests, though only where this is commensurate with the duty of confidentiality and the patient's wishes.

As explained, some forms of medical treatment will be lawful even in the absence of the patient's consent if the procedures are in the patient's best interests and are necessary to ensure improvement or prevent deterioration in health. This is known as the '*doctrine of necessity*' and is not necessarily confined to emergency situations. However, doctors may *not* be justified in proceeding, even in an emergency, if the person is known to have objections to all or some of the treatment.

Guidance has been given by the courts in the case of *Ms B and NHS Hospital (Trust 2002)* on the approach doctors should take where a patient is refusing medical or surgical treatment and there is doubt about his or her mental capacity (*see pages 19–21*).

Patient confidentiality

All patients have a right to privacy and to control information about themselves. Where the patient has impaired capacity, this right must

be balanced with protection of their interests. Carers and other people close to the person lacking capacity will be involved in best interests and healthcare decisions (unless the patient does not want them to be), but there should not be unnecessary or widespread disclosure of identifiable personal health information in such cases without the person's valid consent.

Planning for future healthcare

While they still have capacity, people can state their wishes about the forms of medical treatment which they would or would not be prepared to consent to if they should subsequently lose capacity to decide for themselves. This is known as an *advance statement*, *advance directive* or *living will*.

If the person wishes to change his or her mind about an advance statement, they can simply destroy the written document and inform everyone who knew about it that it is no longer valid. An advance statement can also be withdrawn verbally, and clinicians should note this on the person's records. While the person remains competent, he or she can make a new statement at any time.

What can an advance statement include?

There are various types of advance statement:

- ▶ a requesting statement giving someone's aspirations and preferences
- ▶ a statement of general beliefs and aspects of life which someone values
- ▶ a statement naming someone who should be consulted at the time a decision needs to be made

- ▶ a clear instruction *refusing* some or all medical treatments. This is often called an *advance directive*
- ▶ a statement requesting certain types of treatment which someone would want to receive in certain circumstances; and
- ▶ a statement setting out a degree of irreversible deterioration after which no life-sustaining treatment should be given.

Advance statements can be a combination of some or all of the above.

An advance statement *cannot* require a doctor to do anything which is not lawful, including action taken with the purpose of ending the patient's life.

Are advance statements legally binding?

Health professionals are *not* legally bound to provide treatment requested in advance if it conflicts with their professional judgement on what is clinically necessary or appropriate. Nevertheless, they should take the person's wishes into account in deciding what is in their best interests.

They are, however, legally bound by an advance statement *refusing* treatment, even if they, relatives or carers disagree with it, as long as:

- ▶ the refusal was made while the person still had mental capacity and he or she understood the implications of their decision;
- ▶ it is clear and applicable in the particular circumstances in which treatment is proposed; and
- ▶ it was made without undue pressure from other people and there is no reason to believe the person has changed their mind.

However, advance refusals of treatment apply *only* where the person has lost capacity – a contemporaneous, competent decision *always* overrides an advance refusal. In cases where there is genuine doubt or ambiguity about the person's intention or capacity at the time the statement was made, healthcare professionals should adopt a best interests approach until clarification is obtained. See the guidance given in the case of *Ms B and NHS Hospital Trust* at pages 19–21.

Healthcare professionals should follow any guidance provided by their local Health Trust on advance refusals of treatment. Advice can also be sought from professional, regulatory or indemnifying organisations or legal advisors.

Further guidance

See pages 22-23 under:

▶ ***Advance statements***

Assessing capacity

Confidentiality

Consent to examination and treatment

4. Applications to the High Court

The courts have identified certain circumstances when healthcare professionals or others must make an application to the High Court.

These are:

- ▶ where there is serious uncertainty about the patient's capacity to consent, or their best interests; or
- ▶ where there is serious unresolved disagreement between a patient's family and health professionals.

There are also particular types of treatment which can only be carried out without the patient's consent if the Court has authorised them.

These are:

- ▶ sterilisation for contraceptive purposes
- ▶ donation of tissue, including bone marrow; or
- ▶ withdrawal of nutrition and hydration from a patient in a permanent vegetative state.

The Court can also make a declaration on the following personal welfare matters:

- ▶ where the person should live, for example with particular family members or in residential or nursing home care
- ▶ whether the person should have contact with other family members, for example after the family has been split by divorce; or
- ▶ where there is serious uncertainty as to the patient's best interests or capacity to consent.

In health or welfare cases where the person lacks capacity to be able to instruct their own solicitor, the Official Solicitor will usually be appointed to act on the person's behalf.

There may be other circumstances when it would be advisable to seek the decision of the Court before proceeding with the treatment, for example in complex or serious cases.

The guidance given in the case of *Ms B and NHS Hospital Trust* sets out the principles to be followed in applications to the Court when the patient's capacity to consent is in doubt (*see pages 19–21*).

In such cases, healthcare professionals should consult their professional, regulatory or indemnifying organisations and legal advisors. Doctors should also consult their medical defence organisation if they have any detailed medico-legal or ethical queries and concerns.

5. Combating abuse, exploitation and neglect

People who need support or lack capacity to make decisions are vulnerable to abuse and exploitation, simply because they are reliant on the help and support given by others. Healthcare professionals treating patients or attending residents or patients in institutional care have an important role in watching for and reporting the possibility of physical or sexual abuse or exploitation. For example, they may see unexplained bruising or other evidence of physical abuse on elderly patients. A person with severe learning disabilities or difficulties may become distressed or start to display inappropriate sexual behaviour, which could be an indication of sexual abuse.

Local authority Social Services have responsibility, jointly with other relevant agencies, for putting in place effective local strategies for preventing, detecting and dealing with incidents of abuse. Healthcare professionals should be aware of local procedures and joint protocols, including relevant contact details, so that immediate action can be taken if abuse is suspected.

As a basic guide, healthcare professionals should consider the following steps if abuse is suspected:

- ▶ suspicions about the actions of an attorney or receiver can be reported to the Public Guardianship Office
- ▶ if physical or sexual assault is suspected, it is advisable to inform the police immediately. If possible, this should be done with the consent of the person suffering abuse

- ▶ if any form of abuse (for example, neglect) may have occurred, discuss possible action with Social Services; or
- ▶ if there is concern about the care or treatment given to a vulnerable person in a hospital or residential care home, discuss with the managers of the local NHS Trust or with Social Services.

Further guidance

See pages 22–23 under:

- ▶ ***Abuse***
Confidentiality

6. Further information and guidance

Hints for determining best interests

Find out the past and present wishes and feelings of the person and the factors which the person would consider if he or she were able to do so.

Try to find out the person's own wishes and values and any views which they may have held before they lost capacity. Check the patient's medical and nursing notes to see if any record has been made of their views, wishes, likes or dislikes which may be relevant to the proposed treatment. GPs' records may help.

Check that the person has not been unduly influenced by others or that their wishes or views have not changed over time or because of changes in circumstance.

Try to consider everything that may be important to the person, even though it may not be directly relevant to the particular decision which needs to be made. For example, religious, ethnic or cultural values, particular hobbies or interests and likes or dislikes may all be important considerations.

Allow and encourage the person to participate, or improve his or her ability to participate, as fully as possible in the decision-making process.

Always try to consult the person and find out his or her current views. Take time to explain what is happening and the decision that needs to be made. Even if they are unable to take the decision itself, they may have views on issues that affect the decision, and on what is best for them.

Try to find out the best way to communicate with the person, involving where necessary other professionals who can advise on communication methods and techniques. Family members, an independent advocate, speech and language therapists or other professionals may be able to help.

Consult relatives and others, where appropriate and practical, about the person's wishes and feelings and what would be in his or her best interests.

Listen to the views of people close to the person, especially close relatives, partners, or professional carers to try and find out what the patient would have wanted. Close relatives or friends may have a better knowledge of the person's views and wishes or may have a different but equally valid view of what may be best for them. Family members could have other records or documents which may be useful to refer to. However, the person has a right to confidentiality and may not want certain people to be involved in the decision-making process.

Explore any other possible options or alternatives available for achieving the proposed outcome, and consider which option would allow most freedom for the person's future.



Extract from the judgment in the case of *Ms B*

Guidance to doctors

1. There is a presumption that a patient has the mental capacity to make decisions whether to consent or to refuse medical or surgical treatment offered to him/her.
2. If mental capacity is not in issue and the patient, having been given the relevant information and offered the available options, chooses to refuse the treatment, that decision has to be respected by the doctors. Considerations that the best interests of the patient would indicate that the decision should be to consent to the treatment are irrelevant.
3. If there is concern or doubt about the mental capacity of the patient, that doubt should be resolved as soon as possible by doctors within the hospital or NHS Trust or by other normal medical procedures.
4. In the meantime, while the question of capacity is being resolved, the patient must, of course, be cared for in accordance with the judgment of the doctors as to the patient's best interests.
5. If there are difficulties in deciding whether the patient has sufficient mental capacity, particularly if the refusal may have grave consequences for the patient, it is most important that those considering the issue should not confuse the question of mental capacity with the nature of the decisions made by the patient, however grave the consequences. The view of the patient may reflect a difference in values rather than an absence of competence, and the assessment of capacity should

be approached with this firmly in mind. The doctors must not allow their emotional reaction to (or strong disagreement with) the decision of the patient to cloud their judgment in answering the primary question whether the patient has the mental capacity to make the decision.

6. In the rare case where disagreement still exists about competence, it is of the utmost importance that the patient is fully informed of the steps being taken and made a part of the process. If the option of enlisting independent outside expertise is being considered, the doctor should discuss this with the patient so that any referral to a doctor outside the hospital would be, if possible, on a joint basis with the aim of helping both sides to resolve the disagreement. It may be crucial to the prospects of a good outcome that the patient is involved before the referral is made and feels equally engaged in the process.
7. If the hospital is faced with a dilemma which the doctors do not know how to resolve, it must be recognised and further steps taken as a matter of priority. Those in charge must not allow a situation of deadlock or drift to occur.
8. If there is no disagreement about competence but the doctors are for any reason unable to carry out the wishes of the patient, their duty is to find other doctors who will do so.
9. If all appropriate steps to seek independent assistance from medical experts outside the hospital have failed, the NHS Trust should not hesitate to make an application to the High Court or seek the advice of the Official Solicitor.



10. The treating clinicians and the hospital should always have in mind that a seriously physically disabled patient who is mentally competent has the same right to personal autonomy and to make decisions as any other person with mental capacity.

Further guidance

Subject	Title	Available from
Abuse	<i>No Secrets: Guidance on developing/ implementing multi-agency policies and procedures to protect vulnerable adults from abuse</i>	DH Publications Tel: 09701 555 455 www.doh.gov.uk/scg/nosecrets.htm
Abuse	<i>Confidentiality: Protecting and Providing Information</i> (2000)	General Medical Council Tel: 020 7915 3507/3685 www.gmc-uk.org/standards/default.htm
Abuse	<i>Confidentiality and Disclosure of Health Information</i> (1999) (section 9.1)	British Medical Association Tel: 020 7383 6286 www.bma.org.uk
Advance Statements	<i>Advance Statements about Medical Treatment</i> (1995)	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/codeofpractice
Advance statements	<i>Advance Statements? BMA views</i>	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/advancestatements
Applications to the court in medical decisions	<i>Ms B and NHS Hospital Trust 2002</i> (High Court Judgment)	www.courtservice.gov.uk/judgmentsfiles/j1075/B_v_NHS.htm
Applications to the High Court in medical and welfare decisions	<i>Declaratory Proceedings: Medical & Welfare Decisions for Adults who Lack Capacity.</i> (Fam Law 351, July 2001)	Official Solicitor Tel: 020 7911 7127 www.offsol.demon.co.uk/adultdeclarations.htm
Assessing capacity	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers.</i> (BMA and Law Society, 1995 – second edition due 2003)	Available from BMJ Bookshop Tel: 020 7383 6244 www.bma.org.uk/ethics



Subject	Title	Available from
Assessment, admission and compulsory treatment of patients with a mental disorder	<i>Mental Health Act: Code of Practice</i> (1999) (Second edition due 2003)	Department of Health www.doh.gov.uk/pub/docs/doh/mhcop.pdf
Best interests	<i>Consent Tool Kit</i> – BMA	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/consenttoolkit+m
Best interests	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers</i> (BMA and Law Society, 1995 – second edition due 2003)	Available from BMJ Bookshop Tel: 020 7383 6244 www.bma.org.uk/ethics
Confidentiality	<i>Confidentiality: Protecting and Providing Information</i>	General Medical Council Tel: 020 7915 3507/3685 www.gmc-uk.org/standards/default.htm
Confidentiality	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers</i> (BMA and Law Society, 1995 – second edition due 2003)	British Medical Association www.bma.org.uk/ap.nsf/content/consenttoolkit+m
Confidentiality	<i>Confidentiality and Disclosure of Health Information</i> (1999)	British Medical Association www.bma.org.uk/ethics
Consent to examination and treatment	<i>Reference Guide to Consent for Examination and Treatment 2001</i> ; and free booklets for patients, carers and relatives	DH Publications Tel: 09701 555 455 www.doh.gov.uk/consent/guidance.htm
Consent to examination and treatment	<i>Consent Tool Kit</i> – BMA	British Medical Association www.bma.org.uk/ap.nsf/content/consenttoolkit+m
Consent to examination and treatment	<i>Seeking Patients' Consent: the Ethical Considerations</i>	General Medical Council www.gmc-uk.org/standards/default.htm

Subject	Title	Available from
Reform of the law for people with mental incapacity	<i>Mental Incapacity</i> (Law Commission Report No 231 (1995))	The Stationery Office Tel: 0870 600 55 22 www.lawcom.gov.uk/549.htm
Reform of the law for people with mental incapacity	<i>Making Decisions – the Government's proposals for making decisions on behalf of mentally incapacitated adults</i> (1999)	Lord Chancellor's Department www.lcd.gov.uk/consult/family/decision.htm
Reform of the law for people with mental incapacity	<i>Campaign Pack</i>	Making Decisions Alliance Tel: 020 7306 0807 www.makingdecisions.org.uk
Withdrawing treatment	<i>Withholding and Withdrawing Life Prolonging Medical Treatment</i> (2001)	Available from BMJ Bookshop Tel: 020 7383 6244 www.bmjpub.com/withwith/ww.htm
Withdrawing treatment	<i>Withholding and Withdrawing Life Prolonging Treatments: Good practice in decision-making</i>	General Medical Council Tel: 020 7915 3507/3685 www.gmc-uk.org/standards/default.htm

Useful organisations

Organisation	What it is/does	Contact
Action on Elder Abuse	Provides a confidential helpline service for anyone concerned with the abuse of older people and emotional support for those involved.	Astral House 1268 London Road London SW16 4ER Freephone Helpline: 0880 8808 8042 www.elderabuse.org.uk
Age Concern	Provides national information line for older people and their concerns.	Age Concern England Astral House 1268 London Road London SW16 4ER Tel: 020 8765 7200 www.ageconcern.org.uk
Alert	Campaigns against legalised euthanasia. Provides information on matters relating to Living Wills, Advance Directives and Motor Neurone Disease.	27 Walpole Street London SW3 4QS Tel: 020 7730 2800 www.donoharm.org.uk
Alzheimer's Society	Care and research charity for people with all forms of dementia, their families and carers.	Gordon House 10 Green Coat Place London SW1P 1PH Helpline: 0845 300 0336 www.alzheimers.org.uk
British Medical Association	Professional body and trade union representing doctors from all branches of medicines in the UK.	Medical Ethics Department British Medical Association BMA House Tavistock Square London WC1H 9JP Switchboard: 020 7383 6286 www.bma.org.uk

Organisation	What it is/does	Contact
CARERS UK	Looks after family, partners or friends in need of help because they are ill, frail or have a disability.	Ruth Pitter House 20/25 Glasshouse Yard London EC1A 4JT CarersLine: 0808 808 7777 020 7490 8824 www.carersonline.org.uk
Citizen Advocacy Information and Training	Provides advice about citizen advocacy groups in the initial stages of setting up schemes. Runs training days and gives support to existing schemes.	Unit 164 Lee Valley Technopark Ashley Road London N17 9LN Tel: 020 8880 4545 www.citizenadvocacy.org.uk
Counsel and Care	Provides a confidential and free advisory service for people over 60. Gives advice about welfare benefits and provides financial help towards essential care.	Twyman House 16 Bonny Street London NW1 9PG Helpline: 0845 300 7585 www.counselandcare.org.uk
Down's Syndrome Association	Offers help for people with Down's Syndrome.	155 Mitcham Road London SW17 9PG Tel: 020 8682 4001 www.downs-syndrome.org.uk
Foundation for People with Learning Disabilities	Works with people with learning disabilities to improve the quality of their lives.	7th Floor 83 Victoria Street London SW1H 0HW Tel: 020 7802 0300 www.learningdisabilities.org.uk
General Medical Council	Statutory body which sets and monitors professional standards for doctors. Charity whose purpose is the protection, promotion and maintenance of the health and safety of the community.	178 Great Portland Street London W1W 5JE General Enquiries Desk: 020 7580 7642 www.gmc-uk.org

Organisation	What it is/does	Contact
Headway – brain injuries association	Sets up self-help and support groups; provides information, publicity and booklets on patients' problems, and help for families.	4 King Edward Court King Edward Street Nottingham NG1 1EW Helpline: 0808 800 2244 Tel: 0115 924 0800 (Nottingham) 020 7841 0240 (London) www.headway.org.uk
Help the Aged	Promotes and develops practical programmes. Offers free advice through Senior Line and via information leaflets.	St James's Walk Clerkenwell Green London EC1R 0BE Welfare Rights Adviceline: 0808 800 6565 www.helptheaged.org.uk
Linacre Centre for Healthcare Ethics	Catholic bioethics centre producing academic and other material on a range of issues in healthcare, including euthanasia and the withholding and withdrawing of treatment and care. Also provides advice to health practitioners on ethical aspects of their work.	60 Grove End Road London NW8 9NH Tel: 020 7806 4088 www.linacre.org
Medical Defence Union	Provides 24 hour access to advice and assistance with medico-legal and ethical problems to its members.	3 Devonshire Place London W1M 5PE General Enquiries: 020 7202 1500 Membership Helpline: 0800 716376 www.the-mdu.com
Medical Protection Society	Mutual society of doctors and other healthcare workers providing advice and assistance on any legal issue stemming from professional practice.	33 Cavendish Square London W1G 0PS Tel: 0845 605 4000 020 7399 1301 www.mps.org.uk

Organisation	What it is/does	Contact
MedicAlert Foundation	Non-profit-making registered charity providing a life-saving identification system for individuals with hidden medical conditions and allergies.	1 Bridge Wharf 156 Caledonian Road London N1 9UU Tel: 0800 581 420 www.medicalert.org.uk
MENCAP	Offers support for people with a learning disability and their families. Provides specialist information, homes, leisure activities and further education.	123 Golden Lane London EC1Y 0RT Helpline: 0808 808 1111 Tel: 020 7454 0454 www.mencap.org.uk
Mind (National Association for Mental Health)	Mental health charity in England and Wales – works for a better life for everyone with experience of mental distress.	15-19 Broadway Stratford London E15 4BQ Tel: 020 8519 2122 Mindinfo: 08457 660 163 www.mind.org.uk
Motor Neurone Disease Association	Independent charity that offers support to people with Motor Neurone Disease and those who care for them.	PO Box 246 Northampton NN1 2P2 Tel: 01604 250505 Helpline: 08457 626262 www.mndassociation.org.uk
National Autistic Society	UK charity providing information and support for people with autism spectrum disorders and their families. Also provides information for professionals.	393 City Road London EC1V 1NG Tel: 020 7833 2299 Helpline: 0870 600 85 85 www.nas.org.uk
Official Solicitor	Provides representation for minors or adults under legal disability in county court or High Court proceedings in England and Wales. Protects the best interests and human rights of those who are unable to represent themselves in the legal process.	81 Chancery Lane London WC2A 1DD Tel: 020 7911 7127 www.offsol.demon.co.uk



Organisation	What it is/does	Contact
Patients' Association	Provides help and advice to patients and campaigns for change.	PO Box 935 Harrow Middlesex HA1 3YJ Tel: 020 8423 9119 Helpline: 0845 608 4455
Patient Concern	Committed to promoting choice and empowerment for all Health Service users.	PO Box 23732 London SW5 9FY Tel: 020 7373 0794 www.patientconcern.org.uk
The Prevention of Professional Abuse Network POPAN	Helps people abused by health or social care professionals. Provides information, support, and advocacy. Prevents abuse through training and awareness raising.	1 Wyvil Court Wyvil Road London SW8 2TG Tel: 020 7622 6334 Support Line: 0845 4 500 300 www.popan.org.uk
Public Guardianship Office	Provides financial protection services for clients who are not able to manage their financial affairs because of mental incapacity. Supports the families and advisers of the person who is incapable.	Archway Tower 2 Junction Road London N19 5SZ Customer Service Helpline 0845 330 2900 Enquiry Line: 0845 330 2900 www.guardianship.gov.uk
Relatives and Residents Association	Helps with finding the right care home and with costs. Gives practical advice to anyone with an elderly relative or friend living in a home or long-stay hospital.	5 Tavistock Place London WC1H 9SW Adviceline: 020 7916 6055 www.relres.org.uk
RESCARE (The National Society for mentally disabled people in residential care)	Provides information, advice and support to families including legal advice.	Rayner House 23 Higher Hillgate Stockport SK1 3ER Tel: 0161 474 7323 www.rescare.org.uk

Organisation	What it is/does	Contact
Respond	Runs a national helpline for people with learning disabilities, professionals and carers, dealing with the issues of abuse and abusing.	Third Floor 24-32 Stephenson Way London NW1 2HD Helpline: 0808 808 0700 www.respond.org.uk
Rethink (formerly National Schizophrenia Fellowship)	Charity for people who experience severe mental illness and for those who care for them.	17 Oxford Street Southampton SO14 3DJ General Enquiries: 0845 456 0455 Advice Line: 020 8974 6814 www.rethink.org
SANE	Runs a phone helpline giving advice on all forms of mental illness and offering support to sufferers, their friends, families and professionals.	1st Floor Cityside House 40 Adler Street London E1 1EE Helpline: 0845 767 8000 www.sane.org.uk
Scope (Major disability charity with a focus on cerebral palsy)	Provides a wide variety of services for disabled people including accommodation, educational and training facilities, and fieldwork support for disabled people and their families.	6 Market Road London N7 9PW Tel: 020 7619 7257 Cerebral Palsy Helpline: 0808 800 3333 www.scope.org.uk
Speakability	Supports people living with aphasia and their carers.	1 Royal Street London SE1 7LL Tel: 020 7261 9572 Helpline: 080 8808 9572 www.speakability.org.uk

Organisation	What it is/does	Contact
Stroke Association	Provides practical support for people who have had strokes, their families and carers.	Stroke House 240 City Road London EC1V 2PR Tel: 020 7566 0300 Helpline: 0845 30 33 100 www.stroke.org.uk
United Kingdom Homecare Association	Promotes high standards in domiciliary care services. Provides helpline for members and a consultancy service for non-members.	42b Banstead Road Carshalton Surrey SM5 3NW Tel: 020 8288 1551 www.ukhca.co.uk
VOICE UK	Support and action group for people with learning disabilities who have been abused. Puts people in touch with counsellors and other professionals and provides counselling, advice and other services.	PO Box 238 Derby DE1 9NJ The College Business Centre Uttoxeter New Road Derby DE22 3WZ Tel: 0870 013 3965 www.voiceuk.clara.net
Voluntary Euthanasia Society	Provides advice on making an Advance Statement.	13 Prince of Wales Terrace London W8 5PG Tel: 020 7937 7770 www.ves.org.uk

Wellcome Library

Other booklets in this series:

Making Decisions: A guide for legal practitioners
Making Decisions: A guide for social care professionals
Making Decisions: A guide for family and friends
Making Decisions: Planning for future incapacity
Making Decisions: A guide for people with learning difficulties

© Crown copyright 2003

Copies of these booklets are available from:
Mental Incapacity Branch
Family Policy Division 1
Lord Chancellor's Department
4th Floor, Selborne House
56-60 Victoria Street
London SW1E 6QW
www.lcd.gov.uk/family/famfr.htm#part10